Capacity issues at the front door

Lepping, Peter

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The Mental Capacity Act (2005)

The Mental Capacity Act 2005 (MCA) for England and Wales (MoJ, 2005) has for the first time given the public and clinicians a legal framework for the treatment of persons who lack capacity. It is in-keeping with the Human Rights Act 1998 and based on its principles. It created a legal framework for situations where we tended to use Common Law before with its much less well defined and much less structured framework. Whilst the Mental Capacity Act assumes capacity, it provides guidance for capacity testing. In cases where patients lack capacity to make certain decisions at that point in time it provides guidance for clinicians to come to decisions in the patients best interest (NHS, 2016). It gives legal protection to allow the implementation of these decisions, even if patients may need to be coerced. This protects clinicians' their decision making as long as they follow due process. The legislation also allows all of us as members of the public to prepare for the possibility of lacking capacity ourselves in the future. We can now appoint persons we trust for financial (replacing the old Enduring Power of Attorney), as well as social and health decisions with a Lasting Power of Attorney. It provides a judicial appeal process with a court of protection. With its controversial depravation of liberty safeguards (DoLS) it added an element of legislation for more long term decision making in a patient's best interest.

Lack of capacity

Any lack of capacity can be temporary or permanent. Testing capacity will always have to consider the specific question in hand and the possibility that capacity may be fluctuating and changeable. Capacity assessments should be done with a sliding scale approach. This means that the more severe the potential consequences of the decision, the more rigorous and complete capacity has to be. There is plenty of evidence to suggest that as clinicians we tend to significantly overestimate how much capacity our patients have (Lepping, 2011). A meta-analysis of the prevalence of lack of capacity in a variety of medical and psychiatric settings (Lepping et al, 2015) showed that a 34% of medical patients and 45% of psychiatric patients lacked decision making capacity, showing no statistically significant difference between medical and psychiatric patients. The studies included inpatients and outpatients. They patient groups were heterogeneous but all studies used validated capacity assessment tools. Certain patient groups are well known to have higher rates of incapacity, namely patients with dementia, patients with a mini mental state examination score of 20 or below (Patchet et al, 2010), learning disability (Arscott, 1999), delirium, acute mania or psychosis (Vollmann et al, 2003;Owen et al, 2008), neurological illnesses (Dymek et al, 2001) including stroke, and acute intoxication. In another large study examining the prevalence of incapacity and the accuracy of capacity assessments in adult medical patients, the authors concluded that 26% of medical patients lacked capacity compared with 3% of healthy elderly controls. They added that 'while physicians routinely missed the diagnosis of incapacity (only recognising 42% of incapable patients), they were usually correct when they made the diagnosis' (Sessum et al, 2011). This confirms other research suggesting that clinicians are usually correct when they identify incapacity positively, but often miss to identify it. Clinical audits show that documentation using the Mental Capacity Act legislation is nowhere near the expected percentage of patients who lack capacity (Lepping et al, 2010). This implies that as clinicians we do not apply the Mental Capacity Act legislation often enough. This puts patients and clinicians at risk of illegal treatment, regardless whether outcome is considered positive or negative.

Incapacity in hospitals

Emergency departments often see people with acute and temporary problems that impair capacity such as infections, intoxication, severe mental illness or stroke, to mention just the most common ones. These patients commonly get admitted for short periods of time. Often the lack of capacity will be temporary but patients may not be compliant with treatment suggestions during that time. It can then be necessary to investigate and treat patients in their best interest. The Mental Capacity Act facilitates this in the following way:

1) When there is a definite suspicion that a patient may lack capacity to make decisions about investigations or treatment, capacity should always be assessed and the MCA applied if a lack of capacity is established.
2) The patient's capacity is assessed using a sliding scale approach to the assessment (the greater the potential harm, the more complete capacity is required).
3) If the patient lacks capacity it is up to the decision maker, in medical decisions the senior position treating the patient, to decide what is in the patient's best interest. The MCA (Part 1(4)) defines the process of coming to a best interest decision.
4) The treating team can use proportionate and reasonable force for the minimum time necessary to facilitate the best interest decision.
5) The treating team needs to reassess capacity on a regular basis and document all decisions carefully.

Assessing Capacity

In accordance with the Mental Capacity Act any person must be deemed to have capacity until proven otherwise. However, a lack of capacity is possible if a patient has an impairment of, or a disturbance in the functioning of, the mind or brain, whether temporary or permanent (MCA, Part 1(2)). In order to have full capacity a person must be able to understand, retain, weigh up, and communicate a decision. It is up to the clinician to make sure that he or she explains any proposed investigation or treatment in a way that the patient can understand, and every effort has to be made to facilitate understanding. This may mean the use of pictures or other written material, or the help of trusted others who may know the patients way of communicating.

The effort that clinicians have to make to facilitate understanding always depends on the amount of time available. It is obvious that in life threatening emergencies it is not possible to wait for a relative who may only be able to attend hours later. Therefore practical considerations come into play which have to be balanced by the treating clinician. Patients need to be able to retain the information long enough in order to weigh up what they have been told in order to make a decision. This is particularly important in patients with dementia. Patients with mild dementia may have some cognitive impairment but can often retain information long enough to come to a decision. Patients do not have to remember unrelated information but only information relevant to the decision making process. It is usually a very useful starting point to ask a patient what they understood and have them explain what the clinician just told them back to the clinician. This will give the clinician a good idea of the level of understanding and retention of information, and the possible need to expand the information giving process and the capacity assessment.

The ability to weigh up information is possibly the most difficult and most controversial aspect of any capacity assessment. The Mental Capacity Act clearly allows any person to make eccentric or unwise decisions. Case law has also confirmed that even repeated decisions with poor outcome are not in itself a reason to declare someone incapable of making decisions. However, any decision needs to be based on at least a belief in the information given to the patient. In other words, complete denial of the facts by the patient, or complete lack of insight into an illness, do not constitute an adequate weighing up process. Any person is allowed to draw from personal or other experience to come to a decision, even if clinicians may disagree with that experience on a scientific level. However, the decision making process has to be at least to some degree rational and needs to be broadly in-keeping with the information given to the patient. Communication of the decision made is obviously an essential part of the communication between the patient and the clinician. This may of course be impaired by language barriers, a need to use sign language, post stroke or other speech impediments, or most severely impaired consciousness. Evidently, some of these problems can be more easily

rectified than others. To assess capacity the clinician could ask the patient how he or she came to any given conclusion, which tests the ability to communicate and the rationale used by the patient.
The most important aspect in emergency situations remains the need to save life and limb, and practical decisions have to be made bearing in mind clinical urgency. This point is important, particularly in emergency settings. Whilst the Mental Capacity Act clearly requests that any effort should be made to facilitate understanding and decision making, this has to be balanced with the necessity to act in a life threatening emergency. It can in any way easily be documented why certain aspects of the process were suboptimally facilitated in cases of life threatening emergencies.

Coming to a Best Interest Decision

Once lack of capacity is established for a particular decision such as investigations, treatment or the need for a change of accommodation (like a move to a nursing or care home), the obligation falls on the person responsible for that decision (the decision maker) to define what is in the patient's best interest. The overriding importance in coming to that decision is to decide what the patient would have wanted. This is specifically not about the clinician's personal preferences. It attempts to combine what is medically reasonable with an attempt to find out about the patients preferences, values and probable decisions. The clinician may have had a chance to speak with the patient about his or her wishes which will be helpful. It is also helpful to talk to relatives, friends or carers to ascertain the patient's values and wishes. The patient might actually have written a living will which is not legally binding but should give a strong indication of what the patient would have wanted. If the patient has written an advanced refusal in keeping with the MCA this has to be adhered to as long as it is valid and applicable to the situation. Any requests to stop lifesaving treatment falls under specific safeguards in the legislation. The patient may have a Lasting Power of Attorney and appointed a person to make decisions on his or her behalf. If that person has an activated Lasting Power of Attorney for health and social issues, that appointee then acts on the patient's behalf unless they clearly lack capacity themselves or blatantly act against the patient's best interest.
As a decision maker it is important to look at the medium and long term implications of any best interest decision. For example, an investigation may actually have to be followed up by a number of further investigations or treatments. Whilst one investigation may be in the patient's best interest when it is balanced against the level of distress it would cause, multiple follow up investigations may not be. Sometimes suboptimal medical treatment can be in the patient's best interest if it avoids significant distress. For example, in cases of diabetic control in the elderly it may be appropriate to give insulin once a day if it avoids distress to the patient rather than a more optimal 4 times a day regime. These are the best interest decisions that have to be made considering what we know about the patient's wishes and values. However, we also need to balance the level of distress we will cause with the potential benefits of the proposed treatment. If coercion is needed to enforce the best interest decision, the use of coercion should have been considered as part of the best interest decision making process. The Mental Capacity Act sanctions appropriate and reasonable force to make sure that best interest plans can be facilitated. There is in fact a duty of care towards the patient to facilitate a best interest decision but to do it with the least possible force necessary. Best interest decisions should always be the least restrictive alternative.
The Mental Capacity Act is very clear that no person should be subjected to any particular treatment regime merely because of their age, origin, religion, gender, or other feature that may lead to traditional assumptions. In contrast, the legislation is designed to make sure that every treatment plan is individualised. For example, patients may have very different views about their quality of life when facing a particular disability. Equally, even patients who belong to a particular religious group or sect may not follow all rules that the religious community may generally be associated with. So assumptions about people merely because of the fact that they belong to a specific group should be avoided. Of course it may not always be possible to accurately define what the patient would have wanted. In those cases it will be necessary to go on what is known about the patient's past behaviour

and decisions. If even less information is available it may be necessary to assume what the patient would have wanted in good faith. If a person is un-befriended and has only paid carers to speak for him or her, it is necessary to appoint an independent mental capacity advocate (IMCA) if the decision maker makes a decision about serious treatment or a change of accommodation for more than 28 days. The decision maker, usually the treating consultant or the social worker applying for a change of accommodation, is responsible for the capacity assessment and the best interest decision.

The best way of looking at best interest decision making is to see it as an individualised care plan. The best question to ask oneself is: what would the patient want me to do? The Mental Capacity Act and its Code of Practice follow a specific framework to make sure that best interest decisions are individualised and appropriate efforts have been made to find out what the patient would have wanted.

Dementia and Delirium

In an increasingly older hospital population there is an increasing prevalence of diagnosed and undiagnosed delirium (Lange et al, 2019), and delirium in patients with a known or suspected diagnosis of dementia or cognitive impairment (Bickel et al, 2018). The risk factors for delirium are well documented but despite attempts to find acute triggers for a delirium in a particular patient, in one third of cases a cause cannot be identified. In patients who have comorbid dementia or cognitive impairment, delirium can last much longer than expected, in fact it may last up to 6 months. It is common for delirium to last well beyond the immediate trigger and medical signs for that trigger, for example an acute chest infection or urinary tract infection. Patients with dementia are likely to have prolonged problems with confusion and agitation which mean that they may lack capacity to make decisions about their treatment and discharge. In addition, it can be difficult to differentiate symptoms of delirium from ongoing dementia or cognitive impairment, or in fact from an exacerbation of dementia symptoms because the person is in an unfamiliar environment. In these cases it is very important to look at MCA legislation to make sure that best interest decisions can be made and facilitated. It is often not in a patient's best interest to remain on an acute medical ward because of the risks of secondary infections and other problems like immobilisation and institutionalisation. It may therefore be necessary to find temporary alternative placements that are better suited to look after the patient's needs. The Mental Capacity Act encourages clinicians to focus on what is in the best interest for the patient and can be a leverage to make sure that other agencies facilitate that best interest decision. This is particularly important in times when delayed discharges are common and ubiquitous, particularly in DGH's.

Conclusion

The Mental Capacity Act defines how capacity and best interest assessments and decisions should be made. It gives a legal framework to clinicians and social workers who make decisions about investigations, treatments and changes of accommodation (admission to hospital and discharges to places other than home). The main principles of the MCA include that an assumption of capacity should be made but that an assessment is needed when capacity is in doubt. The decision maker is the person who assesses capacity and makes best interest decisions on behalf of patients who lack capacity. The Mental Capacity Act urges clinicians to produce an individualised plans for each patient who lacks capacity that takes into account what the person would have wanted. The legislation gives protection to clinicians even if appropriate and reasonable force is needed to facilitate the best interest plan. The legislation supports striving for positive outcomes but acknowledges patients' rights to make eccentric or unwise decisions. Research has shown that clinicians usually over estimate patients capacity and it is important to increase our awareness of patients who may lack capacity. It

is fundamental that the Mental Capacity Act is used for people who lack capacity and documentation is thorough. This protects patients and clinicians alike.

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